

Bridging the Gap

Noyes, Jane; Pritchard, Aaron; Rees, Sally; Hastings, Richard; Jones, Kat; Mason, Hayley; Hain, Richard; Lidstone, Victoria

Published: 01/10/2014

Publisher's PDF, also known as Version of record

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Noyes, J., Pritchard, A., Rees, S., Hastings, R., Jones, K., Mason, H., Hain, R., & Lidstone, V. (2014). *Bridging the Gap: Transition from Children's to Adult Palliative Care*. Bangor University/Together for Short Lives.

Hawliau Cyffredinol / General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Bridging the Gap: Transition from Children's to Adult Palliative Care

FINAL REPORT

October 2014



Jane Noyes, Aaron Pritchard, Sally Rees, Richard Hastings,
Kath Jones, Hayley Mason, Richard Hain, Victoria Lidstone

This project was funded by Together for Short Lives, a UK wide charity supporting children, young people and their families living with life-limiting and life-threatening conditions.

© Bangor University 2014

This report can be cited as: Noyes J, Pritchard A, Rees S, Hastings R, Jones K, Mason H, Hain R, Lidstone V. (2014)
Bridging the Gap:
Transition from Children's to Adult Palliative Care. Bangor University, United Kingdom.

Contents

Contents	3
Foreword.....	1
Key Findings from the Bridging the Gap Project.....	2
Introduction.....	2
How does children's palliative care currently differ from adult palliative care?	3
How does the Bridging the Gap project 'fit' with other projects on 'Transition' funded by Together for Short Lives?	4
The Bridging the Gap Project.....	6
We did 8 things:	6
Creating a composite palliative care model for young people and young adults with life-limiting and life-threatening conditions	7
What we did:.....	7
What we found:.....	7
Creating a symptom wheel as an aide memoire so that symptom management is recognised throughout transition and beyond.....	8
The Policy and Guidance Review	11
What we did:.....	11
What we found:.....	12
Mention of palliative care in policy and guidance	12
The key worker and key working	15
What we found:.....	15
Figure 4: Channels of communication that the young person and their family manage without a key worker.....	16
Figure 5: Channels of communication that the young person and their family manage with a key worker.....	17
Asking young people, families and practitioners what they thought about their palliative care needs and transition.....	18
What we did:.....	18
What we found:.....	18
Palliative care needs that commonly fell through the gap during and after transition	18

Awareness of condition-specific palliative care needs by key workers and professionals in adult services	19
Transition key working in palliative care	21
Flexible approaches to identifying and meeting continuing palliative care needs during transition	22
Insufficient or no appropriate adult provision to meet their palliative care needs	23
Findings that match with the STEPP project	26
Expanding the role of a key worker, and	28
Developing person-centred care planning tools to address gaps in transition planning	28
What we did:	28
What we produced:	29
The Bridging the Gap care planning toolkit contains:	29
Making a film about the Bridging the Gap Project	31
What we did:	31
Concluding Summary	32
Acknowledgements	34
Bridging the Gap Practice Development Group Members	35
References	36
Appendix 1: The beginning of the Together for Short Lives Transition Care Pathway	41
Support Organisations	42

Foreword

As a young person with life-limited conditions I highly value the research project that has been done. It is highly important to recognise our needs as young adults, who will still have a shorter than normal life span but have, thanks to medical advances, survived our childhoods and now have to go through transition and lose the relationships with paediatric staff that some of us have had all our lives.

There are many issues when you reach eighteen and still need respite care. There are no facilities that are suitable for young adults with very different medical conditions, who have the capability to say yes they want to do a certain thing or not, even if a young adult is non-verbal, they shouldn't be stuck in a bed all day, whatever our conditions we deserve the same level of respite care that we have as a child.

There have been projects like this done before, and although they address what's wrong with the system, unfortunately there isn't any action taken to move things forward

When I had my transition to adult healthcare, mostly it was smooth, but when I was admitted to an adult ward, I was felt alone, frightened and the staff didn't know how to care for me. When I am poorly, I have high care needs, on the ward the staff seemed too busy to be able to help, and although they always did do their best they didn't have enough staff to cope with people like me.

Our conditions are complex, and for most of us always changing, a new medicine, a new symptom and another test the doctors want to do, and there is no emotional support available for us to talk about our conditions, without it being our family, which is hard to do because you don't want to upset them.

To summarise, I'm very grateful and happy to see this project being done, we need people to know about our needs and understand us. I hope my writing has given you a little insight to what my feelings about transition and respite care are.

Emma Roberts
Aged 18



Key Findings from the Bridging the Gap Project...



Introduction

With an **increasing number of young people surviving with life-limiting or life-threatening conditions into adulthood**, understanding their palliative care needs during transition and into adult services is paramount.

'While the entire course of some diseases occurs within childhood, others may persist into adulthood, and the need for palliative care may range from days to years or even decades.'

Watterson & Hain, 2003

How does children's palliative care currently differ from adult palliative care?

Palliative care for children can combine active treatment with palliative management and the holistic family centred model is different to that of adult palliative care.

'Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement'.

(ACT now Together for Short Lives, 2011)

The four groups of children and young people likely to have holistic palliative care needs can be found in Box 1.

Box 1. Categories of Life-Threatening and Life-Limiting Conditions

Category 1: Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.

Examples:

Cancer, irreversible organ failures of heart, liver, kidney.

Category 2: Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.

Examples:

Cystic fibrosis, Duchenne muscular dystrophy.

Category 3: Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years.

Examples:

Batten disease, mucopolysaccharidoses.

Category 4: Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.

Examples:

Severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode.

(Together for Short Lives, February 2013)

In contrast, historically, adult palliative care service models have provided care to individuals with foreseeable terminal care needs, often with cancer and requiring symptom relief and psychological support towards the end of life (Clark & Seymour, 1999).

How does the Bridging the Gap project 'fit' with other projects on 'Transition' funded by Together for Short Lives?

ACT (now Together for Short Lives) published the report 'Palliative Care for Young People, aged 13-24 in 2001 and a Palliative Care Transition Pathway in 2007 (Thornes 2001, ACT 2007). The Bridging the Gap project builds on this important work.

Together for Short Lives also previously funded a review of transition guidance and care pathways to adult services for children and young people with palliative care needs (Doug et al 2011). Findings from the review showed that:

- ❖ The 'key worker' was considered to be a core component of successful transition.
- ❖ There was an important gap as transition guidance and care pathways did not address 'palliative care' as an overall concept.

The Bridging the Gap project was funded to look specifically at addressing this important gap. The primary purpose was to identify and make explicit palliative care elements and needs that current transition guidance do not pay sufficient attention to.

Once we had identified the core palliative care elements, we then wanted to develop the Care Coordination Cymru key worker role description to incorporate key elements of palliative care.

Finally, to fill the gap we produced a person-centred palliative care planning tool and guidance that covers the specific palliative care elements that are most frequently missed or not adequately addressed by current guidance during and after

transition. The tool and guidance can be used with existing transition planning tools for young people with complex needs.

The next step after the Bridging the Gap project has finished is to incorporate learning into the next edition of the Together for Short Lives Transition Care Pathway.

The palliative care focus of the Bridging the Gap project adds additional palliative care-specific information to complement the 'Supporting health transitions for young people with life-limiting conditions: researching evidence of positive practice (STEPP project)'. The STEPP project looked specifically at what was working well in health settings for young people with life-limiting conditions, some of whom have palliative care needs. The report provides examples of best practice, and a guide for practitioners to improve the experience for young people (STEPP Project Research Briefing, 2013).

The Bridging the Gap report is timely in that in January 2014 the Executive Board of the World Health Organization (WHO) adopted a historic stand-alone resolution that calls for the strengthening of palliative care as a component of integrated treatment within the continuum of care.

(Together for Short Lives, 24th January 2014)

The Bridging the Gap Project

We did 8 things:

- 1 We created a composite **palliative care model for young people and young adults with life-limiting and life-threatening conditions** showing the core elements that should be provided by services during transition to adult services **and** once in adult provision.
- 2 Reviewed current transition plans and care pathways and identified the gaps. We then developed a **symptom wheel** as an aide memoire to raise awareness of possible symptoms that young people may experience and need proactive support to manage.
- 3 Looked to see what **key policy and guidance said** about palliative care during transition.
- 4 Developed 'with' and 'without' **key working coordination models** to show how and why key working appears to be a critical factor in a successful multi-agency transition.
- 5 Listened to **young people, family members and practitioners** to establish their perceptions of young people's palliative care needs during transition.
- 6 Used all of the work undertaken thus far and through a **process of consultation** with young people, parents and multi-disciplinary practitioners and hospice partners, we expanded the key working role to include the missing elements of palliative care.
- 7 Developed **person-centred care planning tools and 'how to' guidance** that draw attention to specific palliative care elements that are frequently lost or inadequately addressed during and following transition.
- 8 Finally, we **made a film** to show how important getting transition right is to young people, families and professionals.

Creating a composite palliative care model for young people and young adults with life-limiting and life-threatening conditions

What we did:

We asked experts and used key children's and adult palliative care books, documents and guidelines to develop a composite model showing core palliative care elements for young people and young adults with life-limiting and life-threatening illnesses. The model was refined through consultation with young people, parents and practitioners (including doctors and nurses).

What we found:

The core elements of palliative care were drawn together and are shown in Figure 1.

Figure 1: Composite Model Showing Core Elements of Continuous Holistic Palliative Care During and After Transition from Children's to Adult Services for Young People with Life-Limiting and Life-Threatening conditions.

1	Continuity of health promotion¹, active treatment and holistic palliative care from diagnosis onwards through transition and into adulthood.
2	Continuity of pain and symptom management to ensure that pain and discomfort and other adverse symptoms are kept under control.
3	Continuity of skilled communication and joint decision making inclusive of young people/young adults and their families and carers. Timely and developmentally appropriate and dynamic assessment of mental capacity of young people and young adults in complex decision making.
4	Continuity of family-centred care and person-centred support inclusive of the entire family, including siblings of the young person/young adult.
5	Continuity of key working as a core component of family and person centred palliative care for a young person/young adult; helping to negotiate the multiple services that a young person/young adult and their family may need access to.
6	Continuity of condition-specific care planning/care pathways that refer to the purposive and supportive planning with a young person/young adult for the delivery of their care needs both now and in to the future and through transition to adulthood and beyond.
7	Continuity of advance care, transition and post transition planning to ensure that young people/young adults and their families receive equitable access to the holistic support and care they need in a timely manner.
8	Continuity of multi-agency care to ensure that the young person/young adult is placed at the centre of what can be a complex care system including GP, local hospital, community nursing team, hospice, social services, school

	and higher education, employment and housing services.
9	Continuity of psychological support for both the young person/young adult and for the family.
10	Continuity of short breaks/respite care for the benefit of the young person/young adult and the family.
11	Continuity of end of life care planning including provision for the young person/young adult to die in their own home, if this is their choice.
12	Continuity of bereavement support for the family during the young person/young adult's illness and following their death.

¹ The concept of health promotion as a function of palliative care is derived from the work of Virginia Bennett (2014)- PhD student at Bangor University supervised by Jane Noyes and Richard Hain.

2

Creating a symptom wheel as an aide memoire so that symptom management is recognised throughout transition and beyond

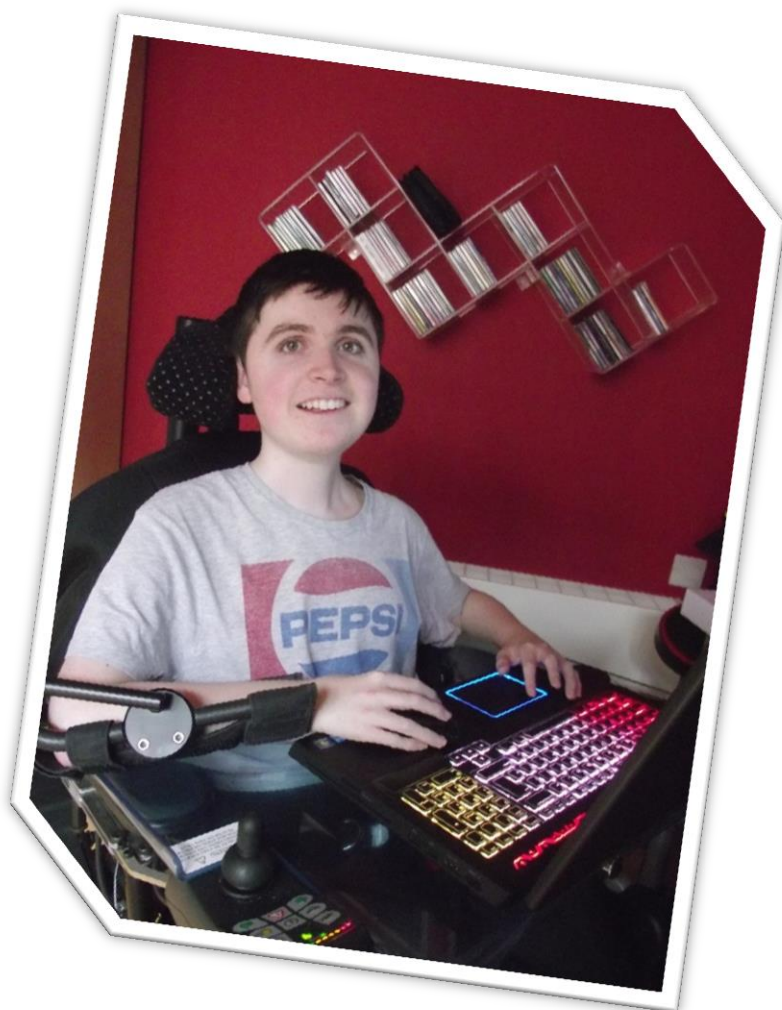
The complex and diverse range of medical symptoms and the importance of symptom management was identified as a key element of palliative care across a range of conditions. Although transition care pathways mention symptom management, it is up to professionals and key workers to ensure that sufficient attention is paid to symptoms and to anticipate future potential symptom management needs. Parents, young people and professionals all said that continuity of symptom management between children's and adult services was challenging. There is also inconsistent mention of symptoms in policy and guidance (see Figure 3).

To ensure that common symptoms and symptom management do not fall through the gap during transition to adult services and beyond, we made a '**wheel of symptoms**' as an aide memoire to help healthcare professionals recognise, plan and palliate symptoms during and after transition to adult services (see Figure. 2).

Key workers who are not healthcare professionals are not expected to develop healthcare plans to manage symptoms but will need knowledge of anticipated individual future healthcare needs in order to think ahead. Key workers who are not healthcare professionals may find the symptom wheel helpful when thinking ahead and anticipating signposting young people to the appropriate people and services to manage their symptoms proactively and effectively.

Figure 2: Symptom Wheel





What we did:

- We searched for and reviewed key child and adult policies, guidelines and documents relevant to the care of young people with palliative care needs.
- From these documents we identified how palliative care needs were perceived and what the intentions were towards providing care for young people in transition with palliative care needs.
- The main elements of palliative care in the model (Figure 1) and symptoms from the symptom wheel (Figure 2) were then mapped onto policies and guidelines to see if palliative care needs were featured (see figure 3).
- This allowed us to identify key gaps in policy and guidance and whether or not young-person specific palliative care needs are firmly rooted in existing guidelines when entering adult palliative care services.
- Gaining a better understanding of how the key worker is intended to work enabled us to develop 'with' and 'without' key worker coordination models to show how and why key workers appear to be a critical success factor.

What we found:

Mention of palliative care in policy and guidance

- Young people age 14-25 years are infrequently recognised as a distinct and separate group from younger children or older adults within palliative care.
- The core elements of palliative care relevant to young people and young adults, whilst not absent, were not consistently mentioned or related to young people or to transition (See Figure 3).
- There is also a lack of guidance on identifying and planning for individual palliative care needs that are important to specific young people and their families.
- Irrespective of whether the young person has or is likely to have palliative care needs, there is also an absence of guidance on how to support young people and their families through transition and in adult services.

Figure 3: Table showing prominence of palliative care concepts in policy and guidance

Key:

- No reference or very brief/underdeveloped reference is made to this element of palliative care
- Some reference is made to this aspect of palliative care
- Is a clearly featured concept/aspect of care within policy/guideline

Policy/Guidance/ Document	Active & Palliative Treatment	Symptom Management	Advanced Care Planning	Multi Agency Care	Psychological Support	Short Breaks/ Respite	End of Life Care	Bereavement Support	Skilled Communication	Family Centred Care	Key Working/ Care Co-ordination	Care pathway/ planning
GENERAL												
NHS Wales Continuing NHS Healthcare (April 2011)	Orange	Red	Red	Orange	Orange	Red	Red	Red	Orange	Orange	Orange	Green
DE (2003) Every Child Matters.	Red	Red	Red	Green	Orange	Red	Red	Red	Orange	Green	Orange	Red
DH (2006) NSF Transition Getting it Right	Orange	Orange	Red	Green	Orange	Red	Red	Red	Green	Orange	Red	Orange
DH (2008) Transition Moving on Well	Orange	Orange	Red	Green	Green	Red	Orange	Orange	Orange	Orange	Green	Green
DH (July 2009) NHS Continuing Healthcare checklist	Orange	Orange	Red	Red	Orange	Red	Red	Red	Orange	Red	Red	Green
DH (2010) NSF Children's Continuing Care Framework	Green	Green	Orange	Green	Green	Orange	Green	Red	Green	Green	Green	Green
DH (2012) National Framework for NHS continuing care and NHS funded nursing care	Green	Orange	Green	Green	Orange	Orange	Green	Red	Green	Orange	Red	Orange
Halton Multi-Agency Transition Strategy	Red	Orange	Red	Green	Orange	Red	Red	Red	Orange	Orange	Orange	Orange
RCN (2004) Adolescent Transition; guidance for nursing staff. RCN	Red	Orange	Red	Orange	Green	Red	Red	Red	Orange	Orange	Red	Green
RCN(2011) Health care service standards	Green	Orange	Red	Green	Green	Orange	Red	Orange	Green	Green	Orange	Orange
Royal College of Physicians (2008) Think transition	Orange	Green	Orange	Green	Green	Red	Red	Red	Green	Green	Green	Orange
Welsh Government (2011) Continuing care guidance	Green	Green	Orange	Green	Green	Red	Green	Red	Orange	Red	Green	Orange
Welsh Assembly Government (2008) All Wales Universal Standards	Red	Orange	Red	Orange	Orange	Red	Red	Red	Green	Red	Green	Green
Welsh Assembly Government (2006) NSF for children and young people	Orange	Orange	Red	Green	Green	Orange	Orange	Red	Orange	Red	Green	Orange

Wright, K (2011) Transition from children's to adult services												
PALLIATIVE CARE												
ACT Transition Care Pathway (April 2007)												
Berkshire Adult Palliative Care Guidelines, (November 2012),												
Commissioning Guidance for Specialist Palliative Care: December 2012.												
NICE Clinical Guideline 140 (May 2012)												
Royal College of Nursing (2012) Competencies children's palliative care												
Royal College of Physicians and British Society of Gastroenterology (2010)												
Scottish Government (2012) Framework for delivery of palliative care												
Thornes, R (2001) Palliative Care for Young People aged 13-24												
Welsh Assembly Government (2008) All Wales Palliative Care Standards - children												
Welsh Government (2013) Together for Health												
W. Midlands Quality Review Service (2012) Quality standards children's palliative care												
World Health Organisation (June 2004) Palliative care symptom management												
World Health Organisation (June 2008) Essential medicines list for children												
CONDITION SPECIFIC												
Foster, C (2010) Transition and HIV												
National Standards for Teenagers and Young Adults with Cancer (June 2011)												
NICE (2005) Guidance on Cancer Services												
NICE Clinical Guideline 137 (2012) The epilepsies												
Radbruch et al (2010) Cachexia and cancer												
Taylor & Shippey (January 2013), Transition of paediatric respiratory patients												
Welsh Assembly Government (2009) Metabolic Diseases												
Yorkshire Cancer Network (2012), Symptom management												

The key worker and key working

The role and function of a key worker is clearly stated in policy. The young person and their family may have a key worker from any of the agencies that they are in contact with. Some agencies provide a designated key worker, whilst others combine the key worker function with other professional roles. For young people with a life-limiting condition their key worker may be a member of the healthcare team.

Palliative care for all children and young people with life-limiting and life-threatening conditions whilst in children's services should be facilitated by key workers using a holistic approach and covering all the elements in Figure 1.

What we found:

- As in Doug et al's review, the ability of a key worker (or a person with the key working function) to negotiate across multi-agency care provision was considered a critical success factor.
- Key workers do not currently appear to have an explicit function to identify and plan for the core elements of palliative care during transition to adult services shown in Figure 1.
- There is no 'how to' guide for key workers to make sure that they plan for all palliative care elements in Figure 1 in a holistic way.
- Key workers do not know what to do when there is no similar or appropriate service in the adult sector and palliative care needs cannot be met.
- Figures 4 and 5 show the hypothetical impact that the key worker is intended to have on making the process of transition simpler and person-centred.

Figures 4 and 5 show a hypothetical 65% reduction in repeated channels of communication potentially needing to be made by a young person and their family when a key worker is introduced into the model.

We calculated the difference in the number of channels of communication with and without a key worker.

Figure 4: Channels of communication that the young person and their family manage **without** a key worker

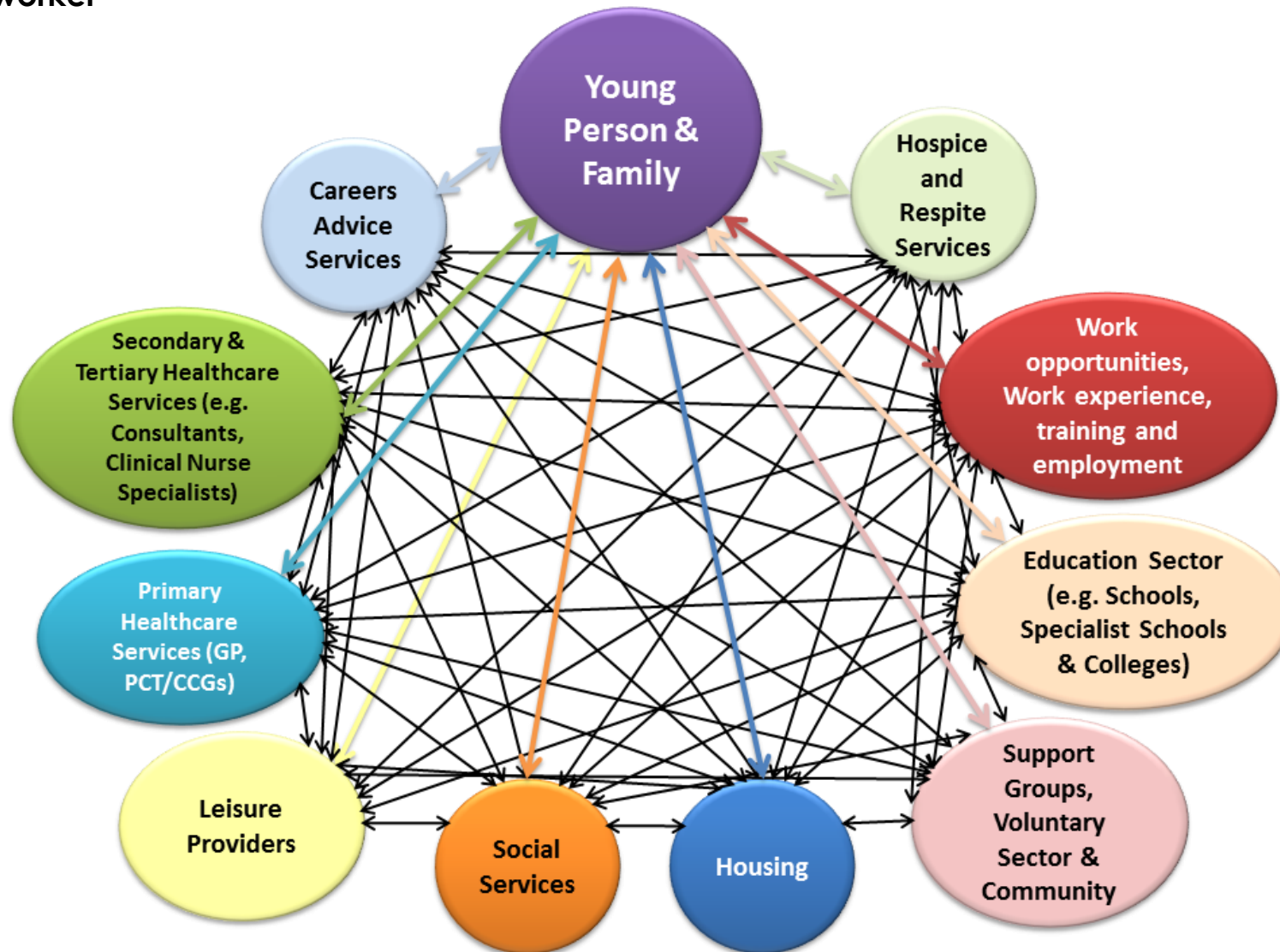
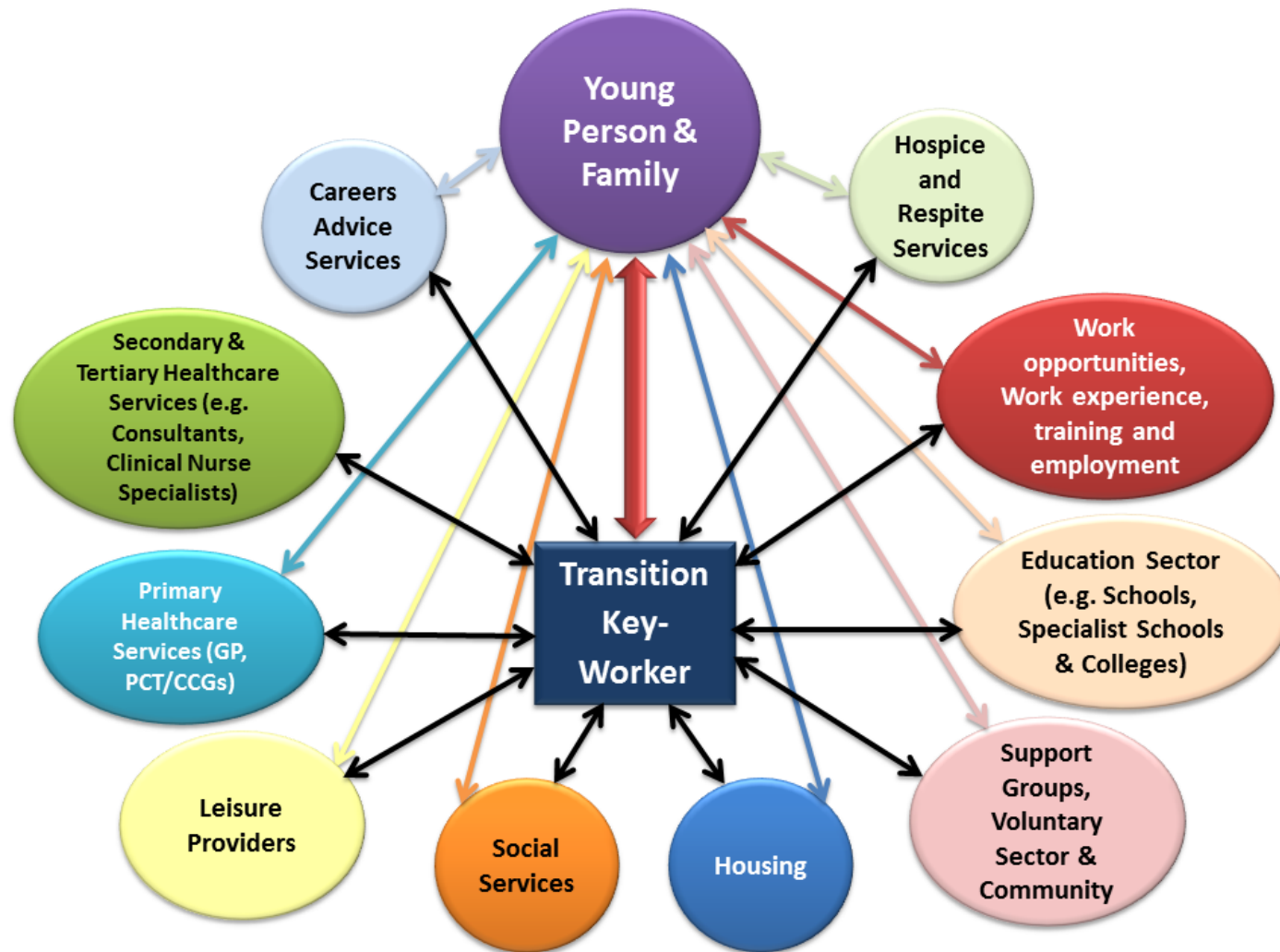


Figure 5: Channels of communication that the young person and their family manage **with** a key worker



Asking young people, families and practitioners what they thought about their palliative care needs and transition

What we did:

We recorded in depth interviews with 21 family members, 9 young people age 14-25 and 8 practitioners.

What we found:

Palliative care needs that commonly fell through the gap during and after transition

The ideal holistic model of palliative care for young people and young adults as shown in Figure 1, quickly became less attainable following transition to current adult services. After transition to adult services some common elements of children's palliative care such as short breaks had disappeared or changed as there was no equivalent adult service. Adult palliative care professionals said that they had expertise in managing conditions such as Muscular Dystrophy and common symptoms such as pain and being sick. Adult professionals were however unfamiliar with many childhood life-limiting and life-threatening conditions. Young people and parents said that once in adult services palliative care professionals did not have sufficient knowledge or awareness of likely condition-specific symptoms or their management. Without clear guidance on the palliative care issues to consider and plan for during and after transition, it was easy to see how some things such as anticipation of condition-specific symptom management fell through the gap.

Awareness of condition-specific palliative care needs by key workers and professionals in adult services

We know from other studies that parents frequently manage serious episodes of illness and symptom management at home without seeking medical help (Noyes et al 2013).

Young people and parents tended to talk about their care needs in more general terms without perceiving these needs as part of 'palliative care'. Although not always mentioned in a transition planning context, their fluctuating and changing condition-specific and symptom management needs included such things as:

- breathing and secretions;
- swallowing and eating difficulties, maintaining weight and gastrostomy care;
- managing pain and discomfort;
- managing seizures (fitting);
- awareness and communication following seizures;
- movement and posture, and
- physical condition and comfort.

Acknowledging and planning for these types of health needs appeared to commonly slip through the transition planning gap. Some young people did not have a home healthcare plan that recorded these needs or likely future needs. Absence of a health plan was more likely if they self-managed at home without regular contact with a nursing service or clinical service and there was no condition-specific equivalent adult speciality or service who would routinely anticipate these needs and be prepared to support management post transition.

A parent shared her experience concerning the management of her son's heart failure:

"...and he didn't see the other consultant then until this year, and when we went in he said 'Oh, we haven't met before', I said 'Oh actually, yeah you have met', and then when he looked at the name he went 'Oh God, [name of son]', he didn't even think [my son] was still here [still alive]."

Mother of young man in his early 20s

Although commonly used palliative care transition plans clearly signpost a need to share information across agencies and for inter-agency co-ordination, it was difficult to locate the triggers in standard transition plans that would ensure that condition-specific health needs would always be picked up and planned for during and after transition.

Symptoms are most likely to be picked up if a healthcare professional undertakes person-centred transition planning and has condition-specific knowledge and experience, or knows the young person very well. Not everyone who performs the transition key working function has relevant health-related experience, and if young people or their carers are not asked or do not know to share this type of information then transition planning for this type of need can and does fall through the gaps.

There was a real fear and actual experience amongst young people and parents that professionals located in adult services had no experience with dealing with their individual complex health and symptom control needs. Many young people and parents said adult professionals lacked awareness of advanced symptoms as well as general

"...They will ask him to lift his arms up, that is quite amusing sometimes, because (name of young man) just sits there, and then after a couple of minutes (name of young man) says, "I know you don't realise it, but I'm trying my hardest to lift my arm up."

Mother of young man, aged 25

awareness of the **condition-specific complex and palliative care needs**. This was particularly the case for relatively rare life-limiting conditions originating in childhood.

One young man talked about his need for adult healthcare professionals to know about his condition and about his overnight feed;

“Even just knowing about the condition and ... just generally knowing ...”

Male, aged over 18

Although young people and their families did not think about specific health needs as ‘palliative care’ needs, in reality their symptoms and symptom control needs added an extra layer of complexity to care planning. When this type of need was not adequately considered or planned for during or after transition, barriers were created that limited young people's choices.

Transition key working in palliative care

Many young people and families did not have someone to perform the key working function during transition despite the prominence of this role within policy and its identification as a core component of a successful transition.

A person that acts as the key worker or who takes on the key working function should develop an overarching transition plan with every young person/young adult with a life-limiting or life-threatening condition, which includes their complex care and management, advance care plans and when appropriate end of life plans.

Young people and parents who had not experienced key working were positive about the role and function in aiding **a personalised and co-ordinated transition**. Their scepticism stemmed from concern about lack of available services for young adults rather than of the key working role itself.

“...Somebody who would sort it out.”

Boy aged 14

“I think it would be absolutely invaluable, I really do. Somebody that can co-ordinate the care between paediatrics and adult services, that can liaise and go between the two, would really, really be helpful. At the moment we’re chasing them and, you know, they’re not responding, but if you had somebody who was working closely with the two maybe they would bridge the gap.”

Community children’s nurse

Appropriate, young person centred services mapped against the composite model in figure 1 are needed beyond 18 years of age. Adult services need to provide short break (called respite and day care in adult services) matched to the diversity of abilities and interests represented by young people entering adult services with **developmentally appropriate sensory and social stimulation**.

Flexible approaches to identifying and meeting continuing palliative care needs during transition

Irrespective of whether their needs were ‘palliative care’ or more general ‘complex care’ needs, young people and their families perceived their ‘needs’ as requiring **flexibility and continuity during transition**. They wanted adult services to provide a continuity of care which was responsive to their evident and fluctuating level of need.

Flexible and adaptable approaches are especially pertinent within the context of palliative care given the **unpredictability of condition-specific trajectories and plateaus and periodic recovery from episodes of acute and critical ill health**.

Like other studies young people and families described many negative and distressing experiences about transition where **their holistic palliative care needs were**

not met and their social lives, education, life choices and quality of life were affected as a result.

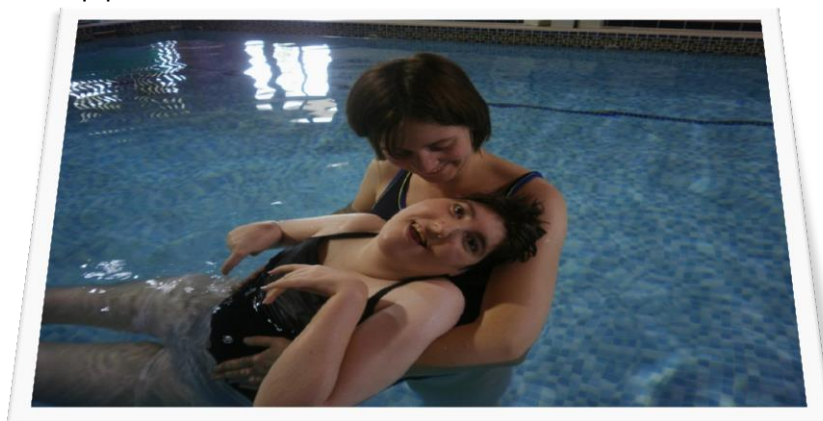
One young man we spoke told us how unprepared services for young adults can be in terms of accommodating specialist care needs. He talked specifically about independent living and University:

...surely they know, think that someone wants to ... live independently. So ... giving them less ... I mean I know when I went to uni they ... obviously they had to give it sort of, but ... they weren't prepared for it.

Young man, aged 20

Insufficient or no appropriate adult provision to meet their palliative care needs

In many cases there was no equivalent condition-specific or adult support service to transition to.



Families described specific palliative care needs and facilities (such as physiotherapy services or a sensory room to meet a child's psychological wellbeing) that could not be met or were not available in the adult sector.

"I feel that once he leaves full time education, and he's not sort of seeing his physio every six weeks or, every other month, that things will just slide and he will deteriorate, because he needs that motivation, he needs someone to sort of come and do it, and as a parent I don't think they give, I know from my experience anyway, (name of boy) doesn't give his all to a parent, yet he would to a health professional. I think that, you know, for me, that is going to slip."

Mother of boy, aged 14

Parents shared their experiences of **family centred and personalised palliative care** they have received from children's hospices. In the words of one of the parents;

"I think that a place like (name of hospice) for some people would be a life line, now we've been there, you know, purely from a pleasure point of view, they've got their hydro pool, and then they've got wonderful facilities for the kids you know they've got computers and they've got TVs and DVDs and they've got a music room, and a playroom and you know I would think that kids would just absolutely look forward to going there and you know, to us, like I say (name of son) is no problem at all, I take him to (name of hospice) because he loves to go there..."

Mother of boy aged 15

And young people expressed a desire for a comparable service in adulthood:

"A hospice for over ... like over nineteen."

Young man aged early 20s

The **appropriateness of adult day care and respite facilities** was an evident concern of practitioners, given the focus of adult facilities on providing care for older adults, more often than not, with interests and care needs distinctly different from younger adults who would like to be able to spend time with people of a similar age.

“the understanding of palliative care in the adult world is very different to the paediatric one, so not only then did we have to start battling with people about her service, but we had to start pointing out to people, what palliative care actually meant, so an example we’d give you is, our GP was asked to support our referral to (name of hospice). In response to that, I only read a letter the other day, which says, he was unable to do that because he couldn’t possibly foresee or predict her dying at 23 or before then.”

Mother of young woman aged 18

Parents and professionals also spoke about palliative care needs being recognised in children’s services but not in adult services.

“No it’s happened to [names colleague] and to myself; I’ve just transferred a young man over, and we thought it was all sorted, I e-mailed the adult equivalent of my manager who said, when we had a meeting to discuss his needs, he didn’t meet [adult] continuing healthcare criteria.

“So What? How can a child not ... not meet, I mean he is totally dependent, he’s [name of condition], he doesn’t ... he isn’t able to feed himself or care for himself in any way, he’s ventilated to [names equipment] at night, and he doesn’t have a significant health need?”

A children’s nurse working in the community shared their encounter with continuing healthcare for young people in transition.

Another key observation was that palliative care symptom groups in the wheel could more easily be managed by a lead children's palliative care specialist or relatively small group of specialists in children's services, whereas in adult services each symptom group could potentially be covered by an individual adult speciality.

Findings that match with the STEPP project

Similar to the STEPP project the importance of person-centred and family-centred planning was evident. Being responsive to uncertainty and the need for planning ahead by developing a range of plans for different scenarios was common to both projects. We add to this the importance of incorporating all the palliative care elements outlined in Figure 1 in each plan that falls within the transition period.

The findings from both projects reinforce the **importance of professionals being able to make better judgements about the capacity of young people to be involved in their own care and decision-making. We add to this the additional communication skills that professionals require but commonly lack when wanting to discuss sensitive palliative care issues.**



"And even if they're told I have capacity, they don't actually... treat me as if I have full capacity."

"Like, they go over your head, they go to mum, or someone from your care team instead of you, and things..."

Young woman aged 18

Young people who had already been through transition commonly continued to experience a lack of involvement in their care and decision-making:

Mum *"One doctor even came out and got me and took me in a separate room, to discuss (name of young man)."*

Young person *"I think I drove off that day..."*

Mum *"You did, and I didn't know where you'd gone. And the doctor said 'Where's my patient gone?' and I said 'I don't think he liked you talking to me behind his back' and he didn't seem to have a clue that he'd done anything....."*

Young Man aged 25 and mother

A personalised approach inclusive of family, though defaulting to the young person themselves, is important for young people to be recognised as an individual and as part of a wider social network.



6

Expanding the role of a key worker, and

7

Developing person-centred care planning tools to address gaps in transition planning

What we did:

We worked with young people, parents and both adult and children's palliative care practitioners and partner hospices to develop a role specification for someone performing the transition key working functions. We also developed person centred planning tools to support key working.

We ensured that these tools would maintain as central the individual young person's **physical, psychological, emotional and social needs** and could be used from childhood through adolescence and in to adulthood.



We consulted with practitioners in **local palliative care forums** and with our partner hospices to make sure that these resources remained grounded in the day to day reality of palliative care.



What we produced:

The Bridging the Gap care planning toolkit contains:

- ❖ 6 care planning tools;
- ❖ one page summary template;
- ❖ action plan template;
- ❖ guidance and completed exemplars;
- ❖ transition key worker palliative care role description;
- ❖ Together for Short Lives transition care pathway - (See appendix 1).

The purpose of the toolkit is to facilitate thinking about and identifying a young person's palliative care needs now and looking ahead to the future. The person-centred tools are used with existing care planning documents to focus on six key health and social elements commonly absent from current transition care plans that may be of relevance to the young person. Identification of needs arising from person-centred assessment of these domains could potentially include needs met by palliative care, including:

- 1. My pain profile.**
- 2. Managing my symptoms and keeping me comfortable.**
- 3. My worries and concerns and how best to support me and my family.**
- 4. How best to support me with short breaks and respite.**
- 5. What is important for you to know about my mobility and how to support me with transfer?**
- 6. Nutrition, food and drink.**

These tools are accompanied by a transition checklist which focuses practitioner and key worker thinking and action planning around what is available in adult services and what palliative care a young person will or is likely to need in the future.



Careful, considered young person involvement ensures that **palliative care needs become a natural part of routine transition planning.**

Palliative care needs in combination with other care needs are then communicated via a one page profile and action plan by the key worker. The job of the key worker is to integrate palliative with other transition needs (education, housing, social and so forth) into a single plan and to liaise with multi-agencies and services through transition to adulthood to ensure flexible continuity of care.

Making a film about the Bridging the Gap Project

What we did:

We worked with a young talented Welsh BAFTA award winning film maker Osian Williams who was studying for his Master of Arts degree in Film at Bangor University. Osian filmed young people, parents, professionals and members of the research team.

The film tells the story about how important it is to include palliative care needs in transition planning. The film is also an accessible audio-visual way to share the key important messages from this project.

The film, guide and toolkit can be located at:

- The Bridging the Gap website:

<http://www.bangor.ac.uk/so/bridging-the-gap/index.php.en>

and

- The Together for Short Lives website – follow the links to resources:

<http://www.togetherforshortlives.org.uk/>

Concluding Summary

Commissioners and professionals in adult palliative care services can use the composite model when planning and evolving adult service provision for young people and young adults with life-limiting and life-threatening illnesses.

We hope that the links between children's and adult palliative care services will continue to grow so that the differences experienced by young people and young adults will become less over time.

Children's and adult services can now integrate the palliative care transition key worker role and function into existing key working arrangements. Key workers are likely to need some familiarisation and training to meet the new holistic palliative care elements that are now central to their role and transition care planning with young people with life-limiting and life-threatening conditions and their families.

When combined with an overarching transition plan, the additional palliative care planning tools and guidance have been designed to help key workers capture the holistic palliative care needs of young people. Although the health needs captured by the tools that require palliative care are mainly 'medical' in origin, the planning tools should embrace a young person's needs in a way that does not detract from the unique and special qualities of each young person and what in their life is important to them.



Acknowledgements

This project was funded by Together for Short Lives, a UK wide charity supporting children, young people and their families living with life-limiting conditions and life-threatening conditions.

We would like to thank everyone who has provided advice and feedback during the course of this project and our Practice Development Task Group, and Shan Pritchard for supporting analysis and report production.

Particular thanks to Osian Williams and Aaron J Cooper for their expertise in helping us to make a short film that reports the key messages from this project.

Above all we would like to thank all the young people and their families who so willingly and generously gave of their time to take part in this research and the staff from the children's hospices that made the project possible.

Bridging the Gap Practice Development Group Members

Dr Janet Appleby	Transition Lead, St David's Hospice
Lizzie Chambers	Development Director, Together for Short Lives
Ann Davies	Development Co-ordinator Care Co-ordination Network Cymru
Nia Rosser-Hughes	Clinical Services Manager, St David's Hospice
Kath Jones	Director of Care, Hope House/Ty Gobaith
Margaret Jones	Parent
Hayley Mason	Family Support Practitioner, Ty Hafan
Dr Helen Mitchell	Palliative Care Consultant, North Wales
Prof. Jane Noyes	Professor of Health Services Research and Child Health, Bangor University
Sam Povah	Young Person
Aaron Pritchard	Research Officer, Bridging the Gap, Bangor University
Dinah Prime	Parent
Sally Rees	Director, Care Co-ordination Network Cymru
Karen Wright	Outreach Team Manager, Hope House

References

ACT (2007) The Transition Care Pathway, A Framework for the Development of Integrated Multi-Agency Care Pathways for Young People with Life-threatening and Life-limiting Conditions. ACT: Bristol

ACT (2009) A Guide to the Development of Children's Palliative Care Services 3rd edition. 2009. Report No.: ISBN 1 898 447 09 8.

Berkshire Adult Palliative Care Guidelines, Section 1: Pain (November 2012), Version 2, Berkshire. Available at: <http://www.royalberkshire.nhs.uk/pdf/Palliative%20Care%201%20Adult%20Guidelines%20PAIN.pdf> (accessed 16th December 2013)

Bennett V, Noyes J, Hain R. Health promoting palliative care for children and young people. Internal working paper, Bangor University. Available from Virginia Bennett, School of Healthcare Sciences.

Clark, D., and Seymour, J. (1999) Reflections on Palliative Care. Series: Facing Death . The Open University Press, Buckingham, England. ISBN 9780335194544.

Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, December 2012. Guidance document published collaboratively with the Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care, and Palliative Care Section of the Royal Society of Medicine, London, UK.

Department of Education (2003) Every Child Matters. Department of Education. <http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/CM5860.pdf>

Department of Health (2006) National Service Framework for Children, Young People and Maternity Services, Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services.

Department of Health (2008) Transition: moving on well; a good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability. DH, England.

http://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf

Department of Health (July 2009) NHS Continuing Healthcare Checklist. Department of Health.

Department of Health (2010) National Framework for Children and Young People's Continuing Care. Department of Health.

<http://www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/National-framework-for-continuing-care-england.pdf>

Department of Health (2012) National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. Department of Health.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf

Doug, M., Adi, Y., Williams, J., Paul, M., Kelly, D., Petchey, R., Carter, Y.H. (2011), Transition to Adult Services for Children and Young People with Palliative Care Needs: A Systematic Review, *BMJ Supportive Palliative Care* Vol. 1(2): 167-173

East Cheshire NHS Trust (July 2011) Pain and Symptom Control Guidelines, Palliative Care 3rd Edition. Greater Manchester and Cheshire Cancer Network. East Cheshire NHS Trust.

Foster, C (Sept 2010) CHIVA Guidance on Transition for Adolescents living with HIV. Children's HIV Association.

<http://www.chiva.org.uk/files/guidelines/transition.pdf>

Halton Multi-Agency Transition Strategy for Young People Aged 14-25 2010-2013 (2010)

<http://www.haltonpartnership.net/childrenstrust/images/stories/pdfs/Multi%20Agency%20Transition%20Strategy.pdf>

National Standards for Teenagers and Young Adults with Cancer aged 16 to 24 years, Consultation (June 2011) available from:

<http://www.wales.nhs.uk/sitesplus/documents/901/National%20Standards%20for%20Teenagers%20and%20Young%20Adults%20with%20Cancer%20aged%2016%20to%2024%20years.pdf>

(accessed 16th December 2013)

NHS Wales (2011) A Guide to the Assessment Process for Continuing NHS Healthcare, available at;
<http://www.wales.nhs.uk/documents/chc%20communication%20tool%20may%202011%20-%20english%20%282%29%20%20final1372011.pdf>

NICE (2005) Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer: The Manual. National Institute for Health and Clinical Excellence
<http://www.nice.org.uk/nicemedia/pdf/C&YPManual.pdf>

NICE Clinical Guideline 137 (2012) The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. National Institute for Health and Clinical Excellence <http://publications.nice.org.uk/the-epilepsies-the-diagnosis-and-management-of-the-epilepsies-in-adults-and-children-in-primary-and-cg137/guidance>

NICE Clinical Guideline 140 (May 2012) Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults. Nice Clinical Guideline 140.

Noyes J, Hastings RP, Lewis M, Hain R, Bennett V, Hobson L, Spencer LH. (2013) Planning ahead with children with life-limiting conditions and their families: Development, implementation and evaluation of the 'My Choices' booklets. BMC Palliat Care. 2013 Feb 5;12:5. doi: 10.1186/1472-684X-12-5.

Radbruch L, Elsner F, Trottenberg P, Strasser F, Fearon K: Clinical practice guidelines on cancer cachexia in advanced cancer patients. Aachen, Department of Palliative Medicine/ European Palliative Care Research Collaborative; 2010.

Royal College of Nursing (2004) Adolescent Transition; guidance for nursing staff. RCN
http://www.rcn.org.uk/_data/assets/pdf_file/0011/78617/002313.pdf

Royal College of Nursing (2011) Health care service standards in caring for neonates, children and young people. Royal College of Nursing.

Royal College of Nursing (2012) RCN competencies: Children's palliative care. RCN, London.

Royal College of Physicians and British Society of Gastroenterology (2010) Oral and feeding difficulties and dilemmas, A guide to practical care, particularly towards the

end of life; Report of a Working Party. London: Royal College of Physicians.

Royal College of Physicians of Edinburgh, Transition Steering Group (2008) Think transition: Developing the essential link between paediatric and adult care.

<http://www.cen.scot.nhs.uk/files/160-think-transition--edinburgh.pdf>

Scottish Government (2012) A Framework for the Delivery of Palliative Care for Children and Young People in Scotland Scottish Children and Young People's Palliative Care Executive Group (SCYPPEX). Scottish Government.

STEPP Project Research Briefing (2013) Making a difference for young adult patients, Together for Short Lives.

Taylor J & Shippey J (2013)

[http://www.eastcheshire.nhs.uk/About-](http://www.eastcheshire.nhs.uk/About-TheTrust/policies/P/Paediatrics%20Transition%20of%20respiratory%20patients%20to%20Adult%20care%201880.pdf)

[TheTrust/policies/P/Paediatrics%20Transition%20of%20respiratory%20patients%20to%20Adult%20care%201880.pdf](http://www.eastcheshire.nhs.uk/About-TheTrust/policies/P/Paediatrics%20Transition%20of%20respiratory%20patients%20to%20Adult%20care%201880.pdf)

Thornes R. (2001) Palliative Care for Young People Aged 13 – 24. Association for Children with Life-threatening or Terminal Conditions & their Families (ACT), Bristol UK.

Together for Short Lives (January 2014) 'WHO adopts resolution on palliative care' available at

http://www.togetherforshortlives.org.uk/news/3931_who_adopts_resolution_on_palliative_care (accessed 20th February 2014)

Watterson, G and Hain, R. D. W (2003) Palliative care: moving forward, *Current Paediatrics* 13, 221-225, doi:10.1016/S0957-5839(03)00002-2

Widdas, A., McNamara, K and Edwards, F. (2013) Core Care Pathway for Children with Life-limiting and Life-threatening Conditions, Third edition, Together for Short Lives.

Welsh Assembly Government (2006) The National Service Framework for Children and Young People and Maternity Services. Cardiff: National Assembly for Wales

Welsh Assembly Government (2008) All Wales Palliative Care Standards for Children and Young People's Specialised Healthcare Services. Cardiff: National Assembly for Wales

Welsh Assembly Government (2008) All Wales Universal Standards for Children and Young People's Specialised Healthcare Services. Cardiff: National Assembly for Wales

Welsh Assembly Government (2009) All Wales Inherited Metabolic Disease Standards for Children and Young People's Specialised Healthcare Services. Cardiff: National Assembly for Wales

<http://www.wales.nhs.uk/sites3/Documents/355/Metabolic%20Eng%20web.pdf>

Welsh Government (2013) Together for Health-Delivering End of Life Care: A Delivery Plan up to 2016 for HHS Wales and its Partners. Welsh Government.

Welsh Government (December 2011) Consultation Document: Children and Young People's Continuing Care Guidance. Cardiff: National Assembly for Wales

http://www.ico.org.uk/about_us/consultations/~media/documents/consultation_responses/Children_and_Young_persons_guidance_consultation_20111220.ashx

West Midlands Quality Review Service and West Midlands Paediatric Palliative Care Network (2012), Quality Standards Children and Young People's Palliative Care, Version 1, November 2012

World Health Organisation (June 2004) Palliative Care: symptom management and end of life care, Integrated Management of Adolescent and Adult Illness: Interim Guidelines for First-Level Facility Health Workers. World Health Organisation.

World Health Organisation (June 2008) Essential Medicines List for Children (EMLC): Palliative Care Consultation Document. World Health Organisation.

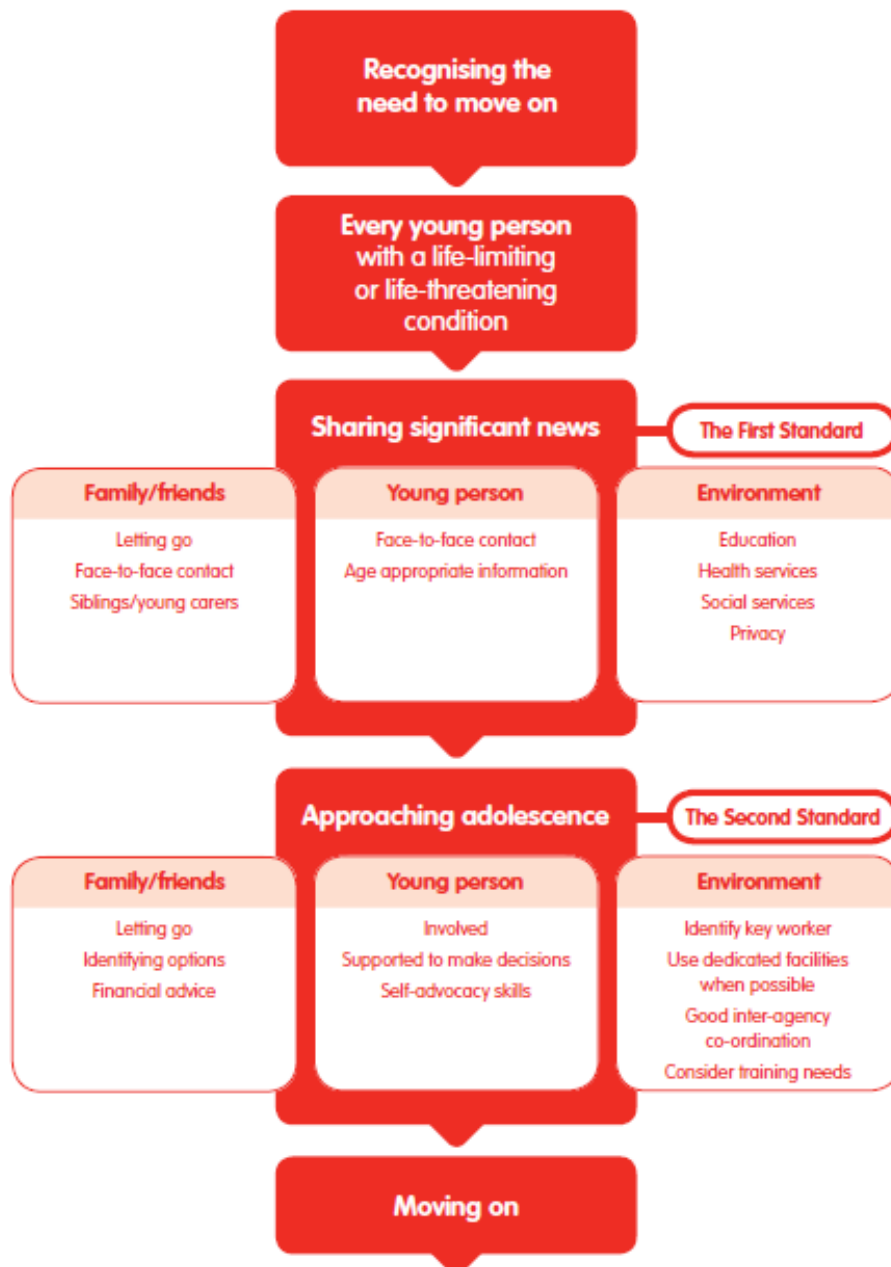
Wright, K (2011) Transition from Children's to Adults' Services for Young People Aged 14 to 25 in Westminster. Westminster's Joint Strategic Needs Assessment.

<https://www.jsna.info/download/get/jsna-westminster-2011-transition-to-adult-services/49.html>

Yorkshire Cancer Network and North East Yorkshire and Humber Clinical Alliance (2012), A Guide to Symptom Management in Palliative Care, Version 5.1

Appendix 1: The beginning of the Together for Short Lives Transition Care Pathway

Diagram 1: Recognising the need to move on



Support Organisations

1. Together for Short Lives

Freephone Helpline: 0808 8088 100

Website: <http://www.togetherforshortlives.org.uk/>

2. Care Co-ordination Network Cymru

Website: <http://en.ccncymru.org.uk/>

3. Helen Sanderson Associates

Website:
<http://www.helensandersonassociates.co.uk/>

4. Contact a Family

Contact a Family Head Office
209-211 City Road, London, EC1V 1JN,
Tel: 020 7608 8700, fax: 020 7608 8701

Free Helpline: 0808 808 3555

Website: <http://www.cafamily.org.uk/>

 **Hope House**
Children's Hospices



PRIFYSGOL
BANGOR
UNIVERSITY


together
for
**short
lives**

THE UNIVERSITY OF
WARWICK

Pontio'r Bwlch
Bridging the Gap



tŷ hafan



ccnuk
care co-ordination network uk
the key working charity



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

